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A systematic review of the contribution of qualitative research to the study of quality of life in children and adolescents with epilepsy

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A sizeable literature focusing on QOL in children and adolescents with epilepsy has been produced over the last few years. However, relatively little emphasis has been placed on defining these issues from direct exploration of children's and adolescents' views. Qualitative methodologies are proposed in this review as an appropriate means of eliciting such information.

This review systematically investigated the extent to which studies of QOL in children and adolescents with epilepsy have used recognised qualitative methodology. Articles for inclusion were identified by searching the term 'epilepsy', combined with 'adolescent(s) and/or child(ren)' and 'psychosocial and/or quality of life'. Selected articles were reviewed and rated using CASP Guidelines for qualitative research by two independent raters.

Seventeen studies were retrieved through literature search. Of these six used some form of qualitative methodology either individually or combined with quantitative methods. However, only one study met quality criteria for selection in this systematic review.

A summary of both selected and excluded studies is presented and methodological limitations discussed. Recommendations for appropriate methodology for investigation of QOL issues in children and adolescents are given.

Key words: adolescence; epilepsy; Quality of Life; focus groups.

INTRODUCTION

Quality of Life (QOL) has been defined as the 'individual's evaluation of the quality of their lives as it relates to their own personal expectations'[1]. When an individual has a chronic condition, for which a total cure is not expected, QOL is considered an important outcome measure for healthcare.

Epilepsy can have a profound impact on psychosocial function and QOL. Studies have shown that epilepsy impedes the development of independence and impairs social function, peer relationships, self-esteem, mood and cognition[2–8]. For children and adolescents, these issues can be particularly challenging, as the development of a healthy self-identity is recognised as a core developmental task and is directly influenced by the development of successful peer relationships and appropriate levels of autonomy[9–11]. Problems with this development have been found to result in depersonalisation and can subsequently lead to low self-esteem, depression, loneliness, anxiety and behavioural problems[2–8,12]. As a result, service providers have become increasingly aware that traditional measures of outcome focusing solely on medical aspects, such as seizure frequency, are not adequate. Subsequently, they have begun to acknowledge that the inclusion of psychosocial factors is vital in providing a holistic approach to care and management[13,14].

A sizeable literature focusing on QOL in children and adolescents with epilepsy has been produced over the last few years[5,15–28]. However, relatively little emphasis has been placed on defining these issues from direct exploration of children's and adolescents' views. As stated above, QOL is the 'individual's evaluation' of the quality of their lives in relation

to 'personal' expectations. It is therefore essential that research studies investigating QOL in children and adolescents focus on direct descriptions and definitions.

Several scales have been developed to investigate QOL and associated risk factors in children and adolescents with epilepsy[3, 29–33]. A recent editorial emphasised that the content of a measurement scale is only likely to be valid if QOL components were derived from a sample of the population in which the tool is to be used[34]. Whilst some of these scales have attempted to involve adolescents and children in the development of items, several methodological issues can be identified which question the validity of the content of all of the above scales.

Firstly, many of these scales have been adapted from those previously designed for use with adults. It can be argued that adaptation of adult scales is inappropriate as this fails to acknowledge important aspects of child and adolescent development and functioning. Secondly, some of these studies have investigated QOL in epilepsy by using generic child-based scales. This is likely to undermine the impact of specific epilepsy-related variables, such as seizures and medication, on QOL. Thirdly, none of these scales has content based solely on the personal views of affected individuals. The majority has either combined personal views of QOL with proxy views or used proxy perspectives of QOL alone. Finally, several of these scales are completed by a proxy informant (parent or clinician) rather than the individual themselves.

Indeed, the majority of the above studies have relied on proxy informants to define QOL in children and adolescents. Proxy reports have been demonstrated to lack validity and it has been noted that the assessment of QOL varies depending on the perspective of the observer[35–37]. Whilst parent and clinician viewpoints are valid in themselves, they are not valid substitutes for the personal perspective and should not be considered as such. Therefore, in proxy-rated scales, not only may the content of the scale be questionable, but also the QOL ratings are invalid as representations of the personal perspective.

Qualitative research provides a solution to the difficulties described above by supplying a methodology that was explicitly developed to investigate experiences from the perspective of affected individuals[38, 39]. Indeed, it has been stated that qualitative research is in fact the most suitable methodology for exploratory research in QOL, where the aim is identification and description of components[40].

The application of qualitative methodology is becoming more common in health-related research. Data collection techniques are flexible enough to be adapted to meet the needs of different target groups and therefore negate the need for proxy informants. A recent review of the use of qualitative methodologies to investigate QOL in children and adolescents, in issues such as asthma, smoking, teenage pregnancy and AIDS, concluded that these approaches are valid and reliable for eliciting information from these age groups[41]. Furthermore, the approach is 'bottom-up' and enables definition of QOL as described directly from individuals, rather than from adaptations of QOL models devised for other groups. Therefore, the validity of identified QOL components is increased, firstly by defining issues from direct exploration and secondly, through the use of a 'bottom-up' approach. In addition, qualitative methodologies facilitate in-depth exploration of issues that would not be possible through quantitative methods alone.

Whilst it is important to explore QOL in children and adolescents with epilepsy, we must be able to conclude that research findings are valid and reliable. Questions can be raised regarding the validity of the findings of any study investigating QOL in children or adolescents which does not elicit views directly from affected individuals or use measures derived directly from their views. As argued, qualitative methodologies are particularly suitable for this type of exploration.

Therefore, this review aimed to systematically investigate the extent to which studies of QOL in children and adolescents with epilepsy have used recognised qualitative methodology. Studies were assessed using quality criteria rating sheets defined by Critical Appraisal Skills Programme (CASP) Guidelines for qualitative research[42]. Emphasis was also given to the composition of the study sample, with reference to the use of proxy informants and the appropriateness of the age range employed. Studies investigating QOL in children and adolescents that did not utilise qualitative techniques were discussed with reference to their limitations.

METHODS

Search strategy

Articles for inclusion in this review were identified by searching the term 'epilepsy', combined with 'adolescent(s) and/or child(ren)' and 'psychosocial and/or quality of life' on the electronic databases: PsychINFO (from 1984 to present); MEDLINE (from 1990 to present); EMBASE (from 1988 to present); Cochrane Library; and CINAHL (from 1982 to present). Further articles were identified through visual search of the bibliographies of retrieved studies and hand searches of key specialist journals: *Epilepsia*, *Seizure* and *Developmental Medicine and Child Neurology*.

Article inclusion and exclusion criteria

Articles were included in the review if they demonstrated the use of sound qualitative methodology (as defined by CASP Guidelines), focused on children or adolescents (5–18 years) with epilepsy, and addressed issues pertaining to QOL or psychosocial function.

Data abstraction

The data abstracted from each article included the methodology used (qualitative, quantitative or combined); the type of informant (self-rated, proxy-rated or mixed); sample size, sample age range, exclusion criteria, measurements used and the issues identified relating to the impact of epilepsy on QOL/psychosocial function. These details are summarised in Tables 1–3.

Study quality criteria

Articles were assessed by two independent raters using rating scales based on CASP Guidelines for quality of qualitative research. These require the demonstration of:

1. an appropriate sampling strategy (e.g. details regarding how and where participants were selected; details provided on non-participants; and consideration of saturation of data in relation to sampling size, i.e. ensuring theoretical saturation is obtained, where no additional data are gained by further collection, to increase reliability of findings);
2. rigorous data analysis (e.g. explanation of how analysis was carried out; attempts to ensure the reliability of data by methods, such as feeding back results to participants, repetition of analysis by more than one researcher and use of triangulation methods, i.e. the combination of methods to take into account as many aspects of a problem as possible);
3. accurate interpretation of data (provision of adequate quotes to support findings);
4. a clear statement of the aims of the research with consideration of qualitative methodology as the most appropriate approach; and
5. transferability of results (i.e. relevance of study to the wider population beyond the study sample, which is increased by use of methods to increase validity and reliability of results and provision of details of participants and non-participants).

As criteria 1–3 related to issues of reliability and validity of findings, it was determined that studies must meet a minimum of these three criteria to be selected for inclusion in this review.

RESULTS

Seventeen studies focusing on the investigation of QOL in children or adolescents with epilepsy were retrieved through literature search. Out of these, six used some form of qualitative methodology either individually or combined with quantitative methods. However, only one of these met quality criteria for inclusion in this systematic review.

Summaries and discussion of retrieved studies will be presented under three headings: Excluded Studies A (studies in which qualitative methodology was not used), Excluded Studies B (studies which used qualitative methodology but did not meet criteria for inclusion in the review) and Included Studies (studies which met criteria for inclusion). A brief discussion of the limitations of the excluded studies will be presented first, followed by discussion of selected studies. The reader is referred to Tables 1–3 for more detailed description of individual studies.

EXCLUDED STUDIES A

Eleven studies were identified through the literature search that focused on children or adolescents with epilepsy, and addressed QOL or psychosocial function but did not use qualitative methodology, and therefore could not be included in the review.

All of these 11 studies used questionnaire designs. Of these, two administered questionnaires to young people only[17,24]; three combined the results of questionnaires completed by both young people and proxies[15,21,22]; and six used questionnaires administered to proxies only[5,20,23,27,29,32]. The majority of these studies investigated correlates of QOL, such as seizure type and frequency. Readers are referred to Table 1 for details of studies.

As discussed previously, proxy reports of QOL are not valid reports of personal representations. However, even in the studies which used self-rated questionnaires[17,24] criticisms can be made regarding the use of a very small sample size ($n = 31$), 18 of whom were seizure free[24] and the use of a scale which was developed using proxy views of QOL[17].

Further criticisms of the above studies relate to the use of generic scales[15,20,22], inadequate exclusion criteria, which did not consider the impact of co-morbid learning disabilities[5,22] and use of a wide age range[32].

Table 1: Excluded Studies A (studies in which qualitative methodology was not used).

Author(s)	Year	Methodology	Measures used	Sample informant	Sample size	Sample age range (years)	Exclusion critera	Results
Devinsky *et al.*[17]	1999	Quantitative	QOLIE-AD-48[30]	Self	197	11–17	Co-morbidity, not co-morbid LD	Older adolescents (aged between 14 and 17 years); those with more severe epilepsy; more symptoms of neurotoxicity; and lower socioeconomic status were more likely to report poor overall HRQOL Older adolescents more likely to perceive a greater negative impact on life and general health, and had more negative attitudes toward epilepsy than younger
Norrby *et al.*[24]	1999	Quantitative	39 bipolar Visual Analogue Scale Questionnaire	Self	31 with epilepsy	9–13	Co-morbidity	No significant difference between children with epilepsy and controls No significant difference between gender, with the exception of vitality, where boys scored higher than girls. Boys also presented with higher self-esteem, although girls had higher scores for elation
Austin *et al.*[15]	1996	Quantitative (longitudinal)	CSCS[44], CBCL[45–47], CATIS[48], APGAR[49]	Mixed	117 with epilepsy, 111 with asthma	12–16 (8–12 years at recruitment)	Co-morbidity (but not clear if same at follow-up)	Adolescents with active epilepsy had lowest levels of QOL in comparison with adolescents with asthma or inactive epilepsy. Even those with inactive epilepsy demonstrated lower levels of QOL compared with adolescents with inactive asthma in relation to several domains of QOL. Severe seizures and female sex were also found to be associated with more problems
Hoare and Mann[22]	1994	Quantitative	SPPC[50], CBCL[45–47]	Mixed	62 with epilepsy, 91 with diabetes	8–15	None reported	Children with epilepsy found to be consistently more behaviourally disturbed and demonstrated lower self-esteem than children with diabetes. Long duration of illness was found to be most consistently associated with poor behavioural adjustment in both groups
Hanai[21]	1996	Quantitative	Survey	Mixed	334 families and teachers	School age (not specified)	None	Major family concerns were ‘the future’ and ‘seizures’. More concern for ‘forget to take medicine’ and ‘school records’ for those in mainstream education More concern for ‘health conditions other than seizures’ and ‘relationships with siblings’ in those not in mainstream education. Main concerns of children were ‘seizures’ and ‘medication’. Over 50% of parents of both groups felt ‘no special’ concerns regarding epilepsy but 29% rated ‘taking medicine every day’ and 29% recorded ‘onset of seizures’ as particular concerns. At school 67% of families felt ‘no special’ concerns but 21% felt was difficulty ‘keeping up with learning’. Some concern ‘prejudices and discrimination may occur’ at school, by both families and teachers, ‘affecting the child’s future’; ‘physical education and participation in school event’; ‘privacy’ and ‘confidentiality is insufficient’. Fifty-five percent of teachers and 60% of families felt “if the seizures can be controlled, children should participate in all activities under individual considerations”. However, a large number of teachers felt the “even if seizures can be controlled, prohibition is necessary for some sports such as swimming”

Sabaz *et al.*[27]	2001	Quantitative	QOLCE[33], CBCL[45–47], CHQ-parent version[51], IPES[29]	Proxy	102 families	4–18	Severe-profound LD	Children with refractory epilepsy without learning disabilities were more likely to have emotional, behavioural and cognitive problems and be less competent in socialising and school performance Overall lower level of QOL in children with learning disabilities and epilepsy than in those without co-morbid learning disabilities, independent of seizure frequency or number of medications Children with learning disabilities had reduced levels of physical function, cognition, emotional well-being, social function and behaviour
Camfield *et al.*[29]	2001	Quantitative		Proxy	97 mothers	12–16	Co-morbidity	Children with IPES scores above the median had parents who were more stressed; more respectful siblings; lower self-esteem; and experienced more emotional problems. The total impact on child and family life was associated with seizure frequency, total number of medications, number of visits to a physician in the previous year and number of nights spent in hospital for neurological reasons
Hoare[5]	1993	Quantitative	Modified IES[52], resources and stress[53,54]	Proxy	108 mothers	5–15	None	Epilepsy has the greatest impact on children with additional disabilities impacting on the management of epilepsy, including side effects from medications; the child's adjustment and development; and restrictions on the family. Early onset intractable epilepsy accompanied by additional disabilities was shown to have a widespread adverse effect on the child and family's QOL and overall adjustment
Hoare and Russell[32]	1995	Quantitative	Impact of Childhood Illness Scale[32]	Proxy	21 parents	6–17	None reported	The most common concerns reported by parents were injury ($n = 7$); alertness ($n = 5$); moodiness ($n = 5$); teasing ($n = 5$); friendships ($n = 5$); maths or reading ($n = 12$); intelligence ($n = 8$); medication ($n = 14$); independence ($n = 5$); care skills ($n = 6$); problems explaining the illness to the child ($n = 9$); and problems with discipline ($n = 6$). The parents of children with poorly controlled epilepsy had more concerns
Hoare *et al.*[23]	2000	Quantitative	Impact of Childhood Illness Scale[32]	Proxy	102 parents of children with epilepsy, 148 with diabetes	9.66 (mean epilepsy), 12 (mean diabetes)	None reported	Children with epilepsy had poorer QOL than those with diabetes with the main effect being the impact on the parents and the family. Impact on development and impact on health were also found in the epilepsy group but not in the diabetes group
Dorenbaum *et al.*[20]	1985	Quantitative	CBCL[45–47]	Proxy	38 mothers	6–16	None	Highest risk for maladjustment for children with epilepsy was in social functioning with scores for overall social functioning and social competence falling well below cut-off in comparison to norms. With younger children no particular area of social maladjustment was represented, however, with adolescents these difficulties were particularly apparent in terms of school competence

Table 2: Excluded Studies B (studies which used qualitative methodology but did not meet criteria for inclusion in the review).

Author(s)	Year	Methodology	Measures used	Sample informant	Sample size	Sample age range (years)	Exclusion critera	Summary of results
Wilde and Haslam[28]	1996	Qualitative	Interviews	Self	24	13–25	Co-morbidity	Majority of sample reported prejudice, especially bullying and teasing whilst at secondary school. Many participants were critical of the medical profession and support services. Most reported feelings of apprehension about telling others about their epilepsy, especially members of the opposite sex and potential employers. Most described supportive, positive relationships with families and close friends. Parental overprotection was rarely reported as a significant problem
Brown[16]	1994	Qualitative/quantitative combined	Blanket survey, analysis of free text	Self	896, 400 completed free text	6–18	None reported	Results from questionnaire: 50% reported seizures made them feel helpless, scared, frustrated or different from others; 41% described feeling panicky about seizures; 33% felt embarrassed and 33% felt angry about seizures; 42% did not mind seizures; 42% felt medication did not work but 82% reported taking medication regularly; 60% felt medication caused tiredness; over 50% believed medication led to poor concentration; 36% said doctors had never explained epilepsy to them and of those who had received information, 51% reported they did not understand what they had been told. Comments in the free text section were described as having focused on the same issues described above
Sabaz *et al*.	2000	Qualitative/quantitative combined (design stage)	Focus groups	Mixed	24 children + parents (8 groups) (pilot study)	4–18	Progressive neurological disorder, visual/hearing	Scale was found to be a reliable and valid measure, sensitive to differences in epilepsy
		Quantitative (validation stage)	QOLCE	Proxy	63 parents	4–18	Impairment epilepsy surgery, NOT co-morbid LD	HRQOL was shown to reduce with increase in seizure severity, independent of age, gender, age at onset or IQ
Cramer *et al*.	1999	Qualitative/quantitative combined (design stage)	Focus groups	Mixed	5–10 adolescents (pilot study)	11–17	Co-morbid, NOT co-morbid LD	Identified eight sub-scales relating to quality of life: epilepsy impact; memory/concentration; attitudes towards epilepsy; physical functioning; stigma; social support; school behaviour and health perceptions
		Quantitative (validation stage)	QOLIE-AD-48	Mixed	197 adolescents + parents	11–17	Co-morbid, NOT co-morbid LD	
Batzel *et al*.	1999	Qualitative/quantitative combined	One-to-one interviews	Mixed	n = not specified (pilot study)	12–19	None reported	139 items were identified with respect to adjustment in eight psychosocial areas: 1. Family background 2. Emotional adjustment 3. Interpersonal adjustment 4. School adjustment 5. Vocational outlook 6. Adjustment to seizures 7. Medical management 8. Antisocial activities
				Mixed	120 adolescents + parents			

Table 3: Included studies.

Author(s)	Year	Methodology	Measures used	Sample informant	Sample size	Sample age range (years)	Exclusion critera	Summary of results
Ronen *et al.*[25,26]	1999, 2001	Qualitative	Focus groups	Self, proxy (results not combined)	29 children (9 groups), 42 parents (17 groups)	6–12	Co-morbidity	Identified five dimensions of QOL: 1.*Theexperienceofepilepsy* 2.*Lifefulfilmentandtimeuse* 3.*Socialissues* 4.*Impactofepilepsy* 5.*Attribution*(*parentsonly*) Main distresses experienced by children were described as relating to daily life restrictions, loss of independence, perception and treatment by peers, unease about how seizures would be handled by outsiders and concern about the adverse effects of medication

EXCLUDED STUDIES B

Five studies were identified through the literature search which used qualitative techniques either alone or combined with quantitative methods but did not demonstrate sufficient quality criteria, or provide sufficient information for assessment of qualitative techniques, to be included in this review. A brief summary of these studies will be presented under the following two headings. More details of these studies can be found in Table 2.

Combined qualitative and quantitative methodology studies

Four studies used a combination of qualitative and quantitative methods to explore QOL[3, 16, 30, 33]. One of these studies[16] described the results of a free text section incorporated into a 30-item questionnaire, containing items on seizure variables; medication; attitudes towards seizures; medication and communication with doctors; and the perceived effect of epilepsy on activities, relationships, school life and personal self-esteem. However, although the study implied the use of qualitative methodology, there was no evidence that the data gathered were analysed using recognised qualitative techniques and therefore the study did not meet any of the criteria for inclusion. Given the large number of participants (896 children, 400 of whom completed the free text section), appropriate analysis of qualitative aspects of the study could have led to rich and descriptive information to complement the data obtained from the overall questionnaire study.

The remaining three studies used qualitative methodology using focus groups[30, 33] or one-to-one interviews[3] to develop specific measures of QOL for children and adolescents with epilepsy. However, insufficient details of the qualitative aspects of these studies were provided to assess quality using the above criteria. Furthermore, no examples of quotes generated from focus groups were presented. In addition, whilst it is commendable that these studies used qualitative methods to elicit information about QOL directly from children and adolescents, criticisms can be made regarding the application of these methods in two of the studies[30, 33]. In one study[33] focus groups were composed of both children and parents. This is likely to have biased results, as children may not have felt they could be open. Furthermore, it is possible that a greater percentage of parent views may simply have been expressed because children felt intimidated by the process. In addition, it is not clear whether the groups combined children across all ages or whether any attempts were made to combine particular age groups. Unfortunately, the authors do not provide any information regarding these issues. Similar criticisms can be made with regards to the other study[30]. Whilst focus groups were composed of just adolescents in this study, topics for discussion were selected from the viewpoint of clinicians and previous literature, rather than items generated spontaneously by the adolescents. Again, this is likely to have reduced the validity of the content of the scale, as it may not be a valid representation of the most significant issues related to QOL for young people with epilepsy.

Furthermore, in all three studies, data from these methods were combined with expert knowledge, literature review and adaptation of existing QOL scales[30, 33]. As argued above, this combination of data is likely to have reduced the validity of QOL as it would have been described by the individuals only. In addition, two of the three scales are completed by a mixture of both self-ratings and proxy ratings[3, 30] and the other is completed by proxy alone[33]. Again, this raises questions about the validity of the QOL measurements made by these scales.

As all three of these studies investigated QOL in epilepsy from the perspective of both adolescents and their carers, it would have been of benefit for both perspectives to be presented separately. As discussed previously, proxy perspectives are valid provided they are described in this way and not used as substitutes for the personal perspective. An analysis of the inter-relationship between the responses of young people and their parents could have contributed to our understanding of QOL for this group of people. However, none of the studies conducted such an analysis.

Qualitative methodology only studies

One study was identified which used one-to-one interviews to investigate the QOL of young people with epilepsy but did not meet criteria for inclusion[28]. The study met criterion 4 but did not provide sufficient information to meet criterion 1 and did not demonstrate sufficient rigor or data to meet criteria 2, 3 or 5. In particular, results were not fed back to participants and no attempt was made to validate themes by independent analysis. In addition, a wide age range was used, with subjects aged between 13 and 25 years of age.

Nevertheless, results from interviews with 24 young people attending outpatient units demonstrated that the majority of the sample reported having been the victims of prejudice, especially bullying and teasing whilst at secondary school. Most reported feelings of apprehension about telling others about their epilepsy, especially members of the opposite sex and potential employers. Most participants described supportive, positive relationships with families and close friends

and parental overprotection was rarely reported as a significant problem. The study concluded, on the basis of a measure of coping which unfortunately was not described, that the majority of the sample was coping well with their condition.

INCLUDED STUDIES

Only one study met criteria for inclusion in this systematic review. The study was presented in two separate papers, the first presenting the results of the study[26] and the other describing the research process[25]. For the purposes of clarity the following discussion considers the papers jointly. Details of the study are summarised in Table 3.

The study met all the criteria 1–5. A qualitative focus group methodology was used to explore the health-related quality of life (HRQOL) in pre-adolescent children aged between 6 years and 10 years 4 months. Children and their parents were involved in identifying QOL components, however, parent and child groups were conducted separately. A clear and justifiable sampling strategy was demonstrated as well as clearly described data collection and rigorous data analysis, using techniques of feeding back to participants, triangulation and analysis by more than one researcher. Data were well presented and it was clear which selected quotes had come from children and which had come from adults. Furthermore, appropriate and explicit inclusion and exclusion criteria were applied, with children who had major co-morbid conditions, such as learning disabilities or who were unable to function in mainstream schools, being excluded.

A further strength of the study was the adaptation of techniques to the target population. 'Child life specialists' were employed as co-planners, moderators and co-designers of the study. Several techniques were used to promote engagement and encourage elicitation of discussion from the children. Examples of techniques were drawing environmental maps (i.e. a drawing of the most important places in the child's life, which the child then used to describe experiences they had had in each place) and using playdough to express emotions about life with epilepsy.

Separate focus groups were conducted for children and parents. In total 9 focus groups, comprising a total of 29 children, and 17 parent groups, totalling 42 parents, were run. Results of data analysis identified five dimensions of QOL, which were described by the authors as follows:

1. The experience of epilepsy (which represented the entire context, setting and situation of coming to terms with and understanding epilepsy);
2. Life fulfilment and time use (which concerned practical issues in day-to-day activities affected by epilepsy);
3. Social issues (which included internal and external social consequences of epilepsy);
4. Impact of epilepsy (which related to personal and psychological impacts); and
5. Attribution (which included explanatory issues, how much and what burdens and concerns were truly related to epilepsy).

The authors noted that the theme of 'attribution' was only identified by parents. The main distresses experienced by children were described as relating to daily life restrictions, loss of independence, perception and treatment by peers, unease about how seizures would be handled by outsiders and concern about the adverse effects of medication. Results from both parent and child groups were combined in the analysis. However, as mentioned earlier, quotes were identified separately.

The above study provides an example of the appropriate application of qualitative methodologies for investigating QOL in children. However, a few criticisms can be made about the study. One is the failure to consider developmental factors in relation to QOL. Children had been stratified into focus groups by age (6–9 and 10–12 year olds) and in terms of duration of epilepsy (under and over 12 months). However, data from these groups were not analysed to report the impact of these variables on content of themes. A secondary analysis comparing these data may have provided useful information on the association between both age and duration of illness on QOL.

SUMMARY OF RESULTS

Seventeen studies were identified through literature search that focused on the investigation of QOL in children or adolescents with epilepsy. However, only six studies investigated QOL using some form of qualitative methodology that focused on the direct views of adolescents, either individually or combined with quantitative methods. Out of these, only one study met quality criteria for inclusion in this systematic review.

DISCUSSION

This review has demonstrated that in spite of the sizeable literature on QOL in children and adolescents with epilepsy, relatively few studies have investigated QOL through direct exploration of children' and adolescents' views. Out of the 17 studies mentioned in this review, only 5 considered the views of the

affected child or adolescent directly and independently from proxies[16, 17, 24–26, 28]. Furthermore, methodological limitations have been highlighted in four of these, related to sample size[24], appropriateness of QOL measurement[17], inadequate presentation of data to support findings[16] and inadequate methods to increase validity of results[28]. The remaining 13 studies used proxy informants or combined self-reports with proxy reports (see Tables 1 and 2).

QOL is the 'individual's evaluation' of the quality of their lives in relation to 'personal' expectations. It is therefore essential that research studies investigating QOL in children and adolescents focus on the direct descriptions and definitions of the individuals themselves. It cannot be reliably concluded that research that does not use direct approaches, or which implements scales developed from proxy investigation of QOL issues, is presenting reliable and valid representations of QOL.

Studies using qualitative approaches to directly investigate QOL in children and adolescents with epilepsy have described restrictions of activities[25, 26], loss of independence[25, 26], difficulties with peer relationships, particularly unease about telling others[25, 26, 28] and experiences of bullying and prejudice[28], although, in general, positive relationships with families were reported[28]. Further concerns were the adverse effects of medication[16, 25, 26] and fear of seizures[16, 28]. It is interesting to note that studies using proxy informants highlighted issues, such as educational attainment and cognitive difficulties[3, 21, 30, 32, 33]. However, as can be seen, these were not identified as significant factors in studies that focused solely on the views of the young person[25, 26, 28]. This perhaps reflects the different perspectives held by proxy informants. Furthermore, limitations have been highlighted with regards to the development of current QOL measurements for children and adolescents with epilepsy[3, 30, 33]. As argued previously, studies using scales developed from the QOL definitions of proxies are not necessarily measuring the most important aspects for young people with epilepsy.

In relation to this point, the majority of the studies that used quantitative methodology, administered questionnaires to examine the correlates of QOL in children and adolescents with epilepsy. Results of these studies can be found in Table 1. Although a quantitative methodology is appropriate for such investigation, studies must ensure that the original content of these questionnaires is valid and that items reliably measure QOL as defined by individuals themselves. A useful approach may be to use a combination of qualitative and quantitative methodologies in the investigation of QOL in children and adolescents, as has been used with other client groups[43]. Qualitative approaches can be used to generate meaningful and valid data that can be used to develop QOL measures. This has the added advantage of being able to use language used by the target group for items in the scale. Once developed, quantitative studies can be conducted using these scales to investigate correlates of QOL in epilepsy, such as seizure frequency and timing of diagnosis.

A final point is that, despite childhood and adolescence incorporating periods of great change, none of the 17 studies explicitly considered the impact of developmental aspects of function in relation to QOL in epilepsy. Analysis of such factors in relation to QOL could contribute greatly to our understanding of QOL in children and adolescents with epilepsy.

CONCLUSIONS

As stated previously QOL has been defined as 'the individual's evaluation of the quality of their lives as it relates to their own personal expectations'[1]. Proxy reports are not valid substitutes for personal perceptions of QOL[35–37]. However, this study has demonstrated that the majority of studies that have investigated QOL in children and adolescents have used proxy reports, either in the definition of QOL or in the development of scales to measure QOL in young people with epilepsy. Inevitably, this raises questions regarding the validity of the findings of these studies. There is a need for studies that focus directly on the views of children and adolescents with epilepsy. Well-designed qualitative studies, such as that conducted by Ronen *et al.*[25, 26], provide an appropriate and valid methodology for such exploration.

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